

## The Story of Alison's Life

This is Alison's Story. MacIntyre supports Alison and she has Down's Syndrome and a diagnosis of dementia.

Her story is one of relationships and the emotional impact that dementia can have on friendship. Alison has a really close relationship with Rachel, her best friend who she also lives with.

### Profile

Name: Alison

Age: currently 53

Where Alison lives: South/East Midlands

Type of support provided by MacIntyre:  
Residential Care



Alison has always been a really social person, enjoying the company of others. A big part of Alison's life has always been socialising, in particular she enjoys dancing and football. Growing up as a child, Alison always wanted to wear football shirts, and still does enjoy wearing her favourite kit – Chelsea - proudly.

A big part of her life was working at MacIntyre's Café and Bakery. Alison used to bake cakes and weigh ingredients; even though she always worked really hard, **work was a real social event for her** and a hub of friendship where she worked and built strong relationships over many years.

Alison still visits MacIntyre's Café regularly and also **attends MacIntyre's Memory Café** on a monthly basis – she enjoys having a cup of tea and cake and the music around her. Both of these activities provide an opportunity to see her friends and **reconnect with those treasured memories**.

**Family has also been extremely important to Alison.** Her mum used to volunteer at MacIntyre but sadly she passed away prior to Alison's dementia. Alison's dad is now in his 90s and in a care home, but Alison is still visited by her brother and sisters.

## Alison's diagnosis

The diagnosis took a long time and a lot of information got missed in translation, but **staff noticed subtle changes in her**. Health Professionals saw Alison's learning disability first, and without evidence, were not moving forward in a diagnosis of dementia. She was also **young to receive her diagnosis** – only in her early - mid 40s – but as we know people with a learning disability are more likely to get dementia at a younger age.

Within MacIntyre, we have noticed hesitancy amongst Health Professionals in diagnosing a person with dementia if they have a learning disability. To combat this, we have been reviewing how we record health across the whole of MacIntyre to ensure we are contributing our part towards gaining a **timely diagnosis** – which we all know is so important.

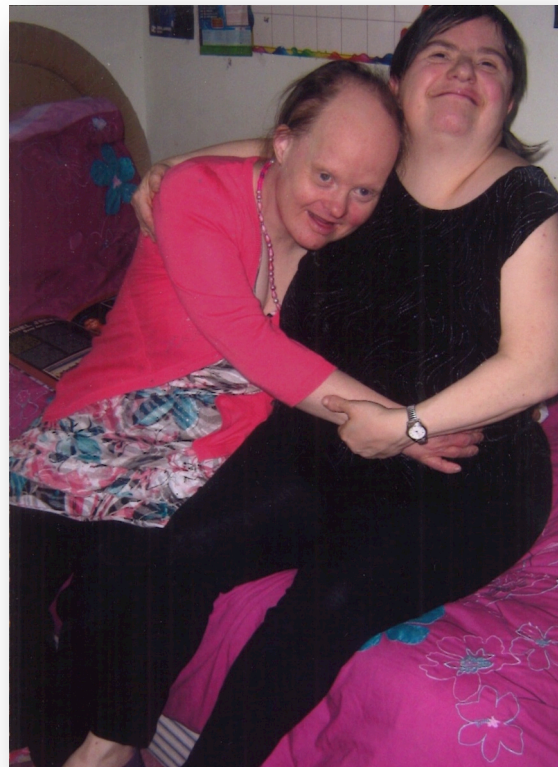
After Alison received her diagnosis, her health has deteriorated quite quickly – and five years ago Health Professionals said that she only had a couple of years to live. We fought on behalf of Alison to have **her stay in her own home**; this is where her friends are, where her support is and where her heart is.

## Sarah's reflection of Alison's diagnosis

I visit Alison as often as I can and she is looking well, most recently I visited her last week. When I speak with her and Rachel, it is **so clear to see how strong their bond is**. They have been friends for a lifetime, and the diagnosis has been a hard time for them, as it would be for any of us. Rachel often shares that **she wishes the dementia would go away** – don't we all?

If you want to find out more, our Registered Manager, Sarah Lancaster has made a series of films that resonate closely to this topic. We have 6 films that overall cover the **Emotional Impact of Dementia on Everyone**. They can be found on our website, and are a really fantastic resource to share with staff.

Visit: <http://bit.ly/RegisteredManager>



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